

February 23, 2017

Thank you, Senator Osten, Senator Formica, Representative Walker, Representative Ziobron and distinguished members of the Appropriations Committee:

My name is Nancy Clarke and I live in Westport with my husband and our 24 year old son, who has autism and an intellectual disability. Our daughter is currently away at college. I am here to testify on the impact of the Governor's budget on people with intellectual and developmental disabilities and their families.

That the words WAITING LIST are spoken here with such frequency and fluency and with so much more compassion than ever before, tells me that progress is being made. I sincerely thank you for that. Thank you specifically to all the members of the IDD Caucus. And I thank the people sitting behind me (at the LOB) who are here advocating, tirelessly, in such personal and impactful ways.

When I saw that this year's budget included an initiative to address the WAITING LIST, I was heartened. But that good feeling didn't last long because I saw that this would be mainly at the expense of Day Programs for new graduates for the next TWO YEARS and Behavioral Services Program! This is just so wrong for so many reasons!!!

First, with respect to the approximately 690 new graduates that this would impact over the next two years: Imagine, graduating at age 21 from school, where there was structure, socialization, and a goal oriented day, and now you will be at home without structure, with nothing. Eighteen years of hard work on the part of schools and communities, and all of these young people wind up at home, isolated. This is not just a terrible cut for the young people involved, but for their parents. More than likely, one of the parents/guardians would need to quit a job in order to stay at home to care for their adult child because in most cases it is unsafe to leave them at home, unattended! Also, this would represent the beginning of yet another WAITING LIST for services. This is just untenable.

Secondly, with respect to the cut to the Behavioral Services Program, unless there are no new families that need these services, or the need for these services has gone down, this is a disaster waiting to happen! These families have children with such complex issues and/or difficult behaviors and they are handling all of this by themselves at home.

At our house, we did not have access to these services BECAUSE I DID NOT KNOW THEY EXISTED so I didn't even know to ask for them! Let me give you an example of how we coped. When our son became agitated, exhibiting all the signs of an impending violent outburst, first I would tell our daughter to go to her room and lock the door. She also knew that this meant—"Do not call the police unless I YELL to you to do so, or if you don't hear me anymore." The police were often called.

The cuts that are on the table have real life consequences to our children— all of our children—and the safety and well-being of our families. Please consider that behind all of these numbers are families that struggle to make it through the day.

Thank you!
Nancy Clarke

